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IMPLICATIONS OF CHRONIC PAIN ON THE QUALITY OF LIFE OF WOMEN WITH FIBROMYALGIA

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ABSTRACT. The aim of this research was to understand the impact of chronic pain on the quality of life of a group of women diagnosed with fibromyalgia. For this, a qualitative study of phenomenological interpretative design was carried out in which 15 women, aged between 23 and 60 years participated. Data analysis was performed with the support of the Atlas.Ti program. The results indicate that the intensity of symptoms, the interference of chronic pain in daily activities, the emotional alterations and the negative cognitions influenced his personal, family, social and work life. The coping strategies assumed by the participants facilitated or hampered the acceptance of the disease. It is concluded that the impact of fibromyalgia on quality of life depends more on coping strategies than on the symptoms of the disease. The support networks facilitate the development of active strategies to confront the disease.

Keywords: Fibromyalgia; quality of life; coping; pain; gender.

IMPLICACIONES DEL DOLOR CRÓNICO EN LA CALIDAD DE VIDA DE MUJERES CON FIBROMIALGIA

RESUMEN. El objetivo de esta investigación fue comprender las implicaciones del dolor crónico en la calidad de vida de un grupo de mujeres diagnosticadas con fibromialgia. Para ello, se realizó un estudio cualitativo de diseño fenomenológico interpretativo en el que participaron 15 mujeres, con edades comprendidas entre los 23 y los 60 años. El análisis de los datos se realizó con el apoyo del programa Atlas.Ti. Los resultados indican que la intensidad de los síntomas, la interferencia del dolor crónico en actividades cotidianas, las alteraciones emocionales y las cogniciones negativas influyeron en su vida personal, familiar, social y laboral. Las estrategias de afrontamiento que asumieron las participantes facilitaron u obstaculizaron la aceptación de la enfermedad. Se concluye que el impacto de la fibromialgia en la calidad de vida depende más de las estrategias de afrontamiento que de los síntomas de la enfermedad. Las redes de apoyo facilitan el desarrollo de estrategias activas para afrontar la enfermedad.

Palabras-clave: Fibromialgia; calidad de vida;afrontamiento; dolor; género

IMPLICAÇÕES DA DOR CRÔNICA NA QUALIDADE DE VIDA DAS MULHERES COM FIBROMIALGIA

RESUMO. O objetivo desta pesquisa foi apreciado pelas implicações da dor crônica na qualidade de vida de um grupo de mulheres diagnosticadas com fibromialgia. Para isso, se realizou um estudo qualitativo de projeto fenomenológico interpretativo e envolvendo 15 mulheres, com idades compreendidas entre os 23 e os 60 anos. A análise dos dados se realizou com o apoio do programa Atlas.Ti. Os resultados indicam que a intensidade dos sintomas, a interferência do dor crónico em atividades cotidianas, as alterações emocionais e as cognições negativas influentes em sua vida pessoal, familiar, social e laboral. As estratégias de enfrentamento que assinalaram os participantes em matéria de impedir a aceitação da doença. Se conclui que o impacto da fibromialgia na qualidade de vida depende das estratégias de enfrentamento dos sintomas da doença. As facilidades de acesso ao sistema de saúde, a qualidade de

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atendimento dos especialistas e o acompanhamento de redes de apoio facilitam o desenvolvimento de estratégias ativas para enfrentar a enfermidade.

Palavras-chave: Fibromialgia; qualidade de vida; enfrentamento; dor, gênero.

Introduction

Fibromyalgia is a rheumatic disease that does not affect the joints and is of an unknown origin. Its symptoms include chronic musculoskeletal pain in specific pressure points (López &Mingote, 2008). Today, around 400 million people in the world suffer from fibromyalgia, which means that nearly five million people are diagnosed with this disease on a yearly basis (Wolfe, Clauw & Fitzcharles, 2012). In Spain, fibromyalgia is prevalent in 2.4% of the adult population (González, Elorza, & Failde, 2010), in the United States, the number fluctuates between 3% and 6% (Wolfe et al., 2012), and in England, Canada and Israel, the percentage of suffering adults is close to 10% (Buskila, 2012). In Latin America, it is estimated that 2.5% of the population in Brazil (Nogueras, Sosa & Calvo, 2010) and 8% in Peru (Moreno et al., 2010) suffer from the disease. Colombia does not have precise data on the epidemiology (Cardona, León, & Cardona, 2014).

The World Health Organization (WHO, 2009) has defined quality of life as the subjective evaluation of people concerning their place in their cultural system and the satisfaction they report according to their ratings of things like achievement, expectations and standard of living. In the past few years, a great number of studies have highlighted the importance studying the socio-demographic, clinical and psychological implication of chronic pain in people diagnosed with fibromyalgia (Collado et al., 2017; Lee et al., 2017; Plazier, Ost, Stassijns, De Ridder & Vanneste, 2015). The chronic pain characteristic of this disease worsens the quality of life of the sufferer and alters their perception of their physical and psychosocial wellbeing (Ataoğlu, Ankaralı, Ankaralı, Ataoğlu & Ölmez, 2017; González et al., 2010; González et al., 2014; Vinaccia & Quiceno, 2012). To that effect, some authors have identified that the aspects that most frequently affect the quality of life for people with this condition are: (a) biological, which determines the location, duration and intensity of the pain; (b) psychological, which is associated with coping mechanisms and adjustment response; and (c) social, which includes the perception and meanings that the person attributes to their disease (Cardona et al., 2014; Lavielle, Clark, Martinez, Mercado & Ryan, 2008).

Research carried out in Spain (Del Pozo et al., 2015; Nogueras et al., 2010; Soriano et al., 2015; Ubago et al., 2008), Holland (Verbunt, Pernot & Smeets, 2008), the United States (Hoffman & Dukes, 2008; Muller et al., 2017) and Colombia (Cardona et al., 2014; Hernández & Cardona, 2015) has identified that the principal factors that interfere with the quality of life in women with fibromyalgia are: (a) the disruptions in their daily activities; (b) the decline in their ability to function individually, in family situations, socially and in the work place; (c) socioeconomic repercussions; (d) the emergence of emotional disturbances; (e) changes in their sleep cycle; (f) poor results of treatments; and (g) the impact produced on their physical and intellectual capacity (Cardona et al., 2014; Sañudo, Corrales & Sañudo, 2013; Söderberg, Strand, Haapala, & Lundman, 2003).

In this regard, symptoms like pain, sleep disturbances, fatigue, exhaustion and depression cause people with this condition to lose motivation to take part in physical, work related and social activities (Armentor, 2017; Del Pozo et al., 2015; González, García & Botella, 2014; Sañudo et al., 2013; Söderberg et al., 2003; Soriano et al., 2015; Yeung, Davis, Aiken & Tennen, 2014). The loss of physical abilities, social roles and the emotional state that accompanies this disease favors physical inactivity, diminishing tolerance to exercise, an increase in the probability of becoming overweight, a rise in feelings of helplessness and the perception of low self-worth (Cardona eta l., 2014; Lavielle et al., 2008; Sener et al., 2016).

Walker, Sofae & Holloway (2006) found that the various bereavements that patients diagnosed with chronic pain experience in the process of this disease may lead them to feelings of despair, influence the manner in which they perceive the pain and interfere in their coping with it. Women with this condition experience changes in their everyday lives, their aspirations, their roles as caregivers and a loss of freedom as well as the autonomy to carry out their activities (González et al., 2014; Jansen, Linder, Ekholm & Ekholm, 2012; Lange & Petermann, 2010; Nogueras et al., 2010). Authors like Rodham, Rance & Blake (2010) claim that many women view their disease as an intruder that modifies their relationship with their partners, friends and family members. Others, like Juuso, Skär, Olsson & Söderberg (2011) and Söderberg et al. (2003), state that these women choose to hide their symptoms from their social environment in order to avoid rejection or judgment. As a consequence, the perceived support and their social relationships are affected.

The manner in which fibromyalgia interferes in the quality of life depends on coping styles and the social, familiar and work related support they perceive (López & Mingote, 2008; Muller et al., 2017). Coping styles are closely related to the meanings that the patient attributes to the pain and to the disease. Studies that relate coping strategies to the quality of life demonstrate that active strategies, directed to solving problems, are related to a lessening of impairments and perception of pain, and therefore also with greater psychological and physical wellbeing (Regier&Parmelee, 2015; Soriano et al., 2015; Ubago et al., 2008). In this line of thinking, active strategies are considered those that allow the sufferer of the disease to persevere with their tasks, distract themselves, perform recreational activities that raise their spirits and exercise. On the other hand, passive strategies include praying, resting, protecting themselves from pain, victimizing themselves and the abuse of alcohol or medication (Biccheri, Roussiau&Mambet, 2016; González et al., 2014).

The objective of this research was to understand the implications of chronic pain in the quality of life in a group of women diagnosed with fibromyalgia. To do this, this work focused on determining the perceptions that these women have about the implications of pain in the quality of their lives and identify the strategies they employed to cope with the changes.

Method

Research design

This study was conducted using a qualitative focus of interpretative phenomenological design, since this approach allows for the description of the meaning of the experiences of the participants from their reality and recognizes the constructive role of the researcher in the interpretation of phenomenon (Willig, 2013).

Participants

The selection of the participants was carried out in an intentional manner and was determined by the saturation criteria. This meant that the number of participants was gradually put together according to the collection and interpretation of data, and the researchers were in constant theoretical, conceptual and methodological reflection during the study. In total, 15 women diagnosed with fibromyalgia between the ages of 23 and 60 years old participated. Table 1 describes their socio-demographic profile.

The inclusion criteria took into account that the participants: (a) were diagnosed with fibromyalgia at least one year prior to the study and (b) that they were between 20 and 60 years old, this being the range in which the disease is most prevalent.

Table 1. *Socio-demographic profile of the participants*

Pseudonym	Age	Socio-economic status	Marital status	Profession	Time of diagnosis
Marta	45	Low	Married	Housewife	2 years
Carmen	57	Middle	Common-law marriage	Commercial Advisor	15 years
Violeta	45	High	Married	Secretary	20 years
Sofía	23	High	Single	Commercial Advisor	2 years
Estela	37	High	Common-law marriage	Housewife	5 years
Gloria	45	Middle	Married	Housewife	16 years
Camila	29	High	Married	Lawyer	5 years
Beatriz	39	Middle	Married	Housewife	2 years
Diana	60	High	Married	Administrator	13 years
Patricia	43	Low	Married	Secretary	20 years
Lina	54	Middle	Married	School Principal	16 years
Verónica	52	High	Married	Housewife	5 years
Natalia	32	Middle	Common-law marriage	Housewife	2 years
Angélica	41	Low	Married	Housewife	3 years
Alejandra	46	Middle	Common-law marriage	Housewife	2 years

Data collection

An in-depth interview was employed as a collection technique that allowed understanding of the phenomenon based on the interpretation of the participants. Four expert judges of the topic verified the relevance, coherence and wording of the questions for the interview guide, according to the research objectives. Based on the comments made by the judges, and a pilot interview, the final questions for the interview guide were drafted. The analysis categories were: (a) implications of chronic pain in the quality of life and (b) coping styles used by the participants with the disease. The categories and subcategories were selected based on the reported experiences by the study population and the conceptual references identified during the review of the literature and the objectives proposed in the research.

Moreover, the *Brief Pain Inventory Questionnaire* (Badia et al., 2003) was used, which is made up of two basic dimensions: (a) pain intensity and (b) the interference of pain in the everyday existence of the subject. The first is composed of four aspects that allow a measurement of the intensity of pain in four levels (maximum, minimum, average and actual). The second dimension consists of a framework made up of seven items whose purpose is to understand the impact of pain in the different areas of the person's life. This standardized instrument is self-administered and is used particularly with patients with chronic diseases. In terms of reliability, this instrument reports a Cronbach alpha coefficient superior to 0.70 for each of its dimensions, with 0.89 for the intensity of pain and 0.87 for the interference in activities (Badia et al., 2003).

In this research, this clinical instrument was used to characterize the intensity of pain perceived by the participants and to measure the interference that this experience has on different aspects of their lives. More than carrying out the measurement of a phenomenon, this questionnaire was applied in order to obtain a wider perspective of the experience of each of the participants by providing elements for interpretation and understanding.

Procedure

During the data collection, contact was established with private health care companies in Cali, Colombia, that specialized in chronic pain management, in order to ask permission to gain access to the population of study. As participants were selected, it was verified that they met with all the established inclusion criteria, and they signed an informed consent once they understood and accepted the terms of the study. This research was approved by the corresponding bodies in the university and was guided by resolution #008430 from 1993 by the Ministry of Health, which sets the scientific guidelines, both technical and administrative, for health research with human subjects in Colombia.

The interviews were conducted between September 2015 and February 2016, in a private office. Depending on the particular needs of each interviewee, additional in-depth sessions were scheduled. This decision was linked to the established saturation principle. On average, the interviews lasted approximately an hour and a half, each.

Data analysis

The interviews were transcribed textually to facilitate later analysis using the categories and subcategories that were established in the Atlas.Ti program (version 7.5). With the objective of reducing possible biases in interpretation, data analysis was carried out by each of the researchers based on the study's categories and following the necessary organization, segmentation and correlation scheme in order to reach saturation (Willig, 2013). The triangulation by researchers was reached using the *Consensual Qualitative Research* (CQR) technique. This widened the researcher's perspectives, and facilitated the systematic comparison of the analysis. Acknowledging the importance of the perspective of the interpreters of the phenomenon of study, the researchers carried out a reflexivity exercise during the process in order to recognize the influence that their subjective realities had on the phenomenon of study.

Results and discussion

This section presents the results of the *Brief Pain Inventory Questionnaire* and the in-depth interviews conducted on the 15 women diagnosed with fibromyalgia who participated in the research. To facilitate the understanding of these findings, the discussion between obtained results in each of the established categories of analysis and the information reported in the literature pertinent to the topic is presented in parallel.

Implications of chronic pain on the quality of life

Pain intensity and interference

The reported results of the *Brief Pain Inventory Questionnaire* allowed for the recognition that the intensity of the perceived pain most frequently by the participants was high (60%), followed by medium (27%) and low (13%). 53% stated that the relief they felt from the pain by taking medication was medium, 20% stated that it was low and 13% high. Likewise, the predominant interferences of pain were with sleep (60%), in general activities (53%), in their emotional states (53%), in daily work (46%), in their ability to walk (40%), in their interpersonal relationships (40%) and in their ability to have fun (40%).

As has been widely reported in the literature, and can be seen in the following lines, the intensity of the symptoms, the interference of chronic pain in everyday activities, the emotional disturbances and negative cognitions directly influence the personal, familiar, work and social life of this population (Ataoğlu et al., 2017; Collado et al., 2017; García et al., 2006; González et al., 2014; Lee et al., 2017; López & Mingote, 2008; Janse et al., 2012; Nogueras et al., 2010; Verbunt et al., 2008).

Decrease in physical and social activities

In the in-depth interviews, the onset of pain in the lives of the participant was identified as a cause for feelings of anger, impotence and sadness. The pain crises they experienced could be so intense that they frequently had to end or postpone the activities they were doing. The moments in which the intensity of the pain lessened created feelings of wellbeing and happiness:

> *One day, I opened my eyes and I said to my husband that I wasn't in pain, because as soon as I open my eyes [normally] I would get head and back aches. I said, "I'm not in pain!" For me, this was a great source of happiness because I had opened my eyes, and nothing (…) There are days when I wish I could just disconnect, I wish I could just take my arm, my head or my legs, put them on a table and forget about them (Angélica, 41 years old).*

The pain provoked a sensation of exhaustion that lasted throughout the day and brought, as a consequence, a decrease in their physical and social activities. In some, the sensation of perceived pain could even bring on an internal struggle against the disease:

> *I feel exhausted during whole day. Sometimes I want to get up and do physical activities or have a social life, but I feel something very heavy that doesn't even let me open my eyes, that knocks me down; it's severe exhaustion, constant pain in each and every joint in my body; the pain keeps me from doing anything. It is really frustrating (Estela, 37 years old).*

The participants felt frustrated by not having control over the symptoms of their disease; as well, they were alone and misunderstood due to the isolation to which they were subjected by their bodies. The quality of their relationships worsened and, in the same way, so did the support they perceived from others.

> *With the pain in my hip, I couldn't do anything; if I walk for a bit, I get tired (…) I don't go out like I used to. The other day, we were invited to a party, but why go if we can't dance. I'm better off if I avoid the pain caused by staying up late. These things are always present, and we end up changing out plans (Estela, 37 years old).*

After being diagnosed, some of the women stated that they suffered disrupted sleep cycles. Difficulty sleeping increased the sensation of tiredness and interfered in different areas of their lives. In order to control the pain, they asserted that they would do certain physical activities like going for a walk, swimming and going to the gym. Some of the women mentioned that doing activities that were physically demanding caused intense pain. Nonetheless, all the women agreed that both, doing physical activities or not doing them, could be a source of pain. Others, on the other hand, employed strategies to minimize the pain like relaxing massages, creams, warm baths in the evening, psychophysical therapies and practicing meditation exercises.

A great number of the participants claimed, along the same lines, that they were afraid that their pain would increase to the point where it would become crippling, or even kill them. For some, the intensity of the pain and the emotional disturbances they felt brought about alarming ideas:

> *As time goes on, the pain becomes more chronic. I'm afraid that this pain that I feel is going to damage my bones. I say to myself, "My God, could it be that I'll be deformed? What consequences will this have further on?" That scares me. The moment will come when I won't be able to stand it (…) "Will I have to depend on someone when I'm 50?" (Violeta, 45 years old).*

As reported in the studies made by Del Pozo et al. (2015), Hoffman & Dukes (2008), Muller et al. (2017), Vinaccia & Quiceno (2012) and Yeung et al. (2014), it was found that the pain, the disrupted sleep and tiredness were the symptoms that most caused an impact on the quality of life of the participants. In the research, specifically those that reported the greatest interference from the symptoms in their daily lives were found to be the ones who had the highest scores in the *Brief Pain Inventory Questionnaire*. The onset of fibromyalgia affected their ability to go about their daily activities, interfered with their social, work related and familiar functions, and altered the perception of their physical and intellectual capacities (Cardona et al., 2014; Hernández & Cardona, 2015; Vinaccia & Quiceno, 2012). This could be explained, in part, due to the current general lack of understanding of the disease (Jansen et al., 2012; Lange & Petermann, 2010; Plazier et al., 2015; Walker et al., 2006).

Emotional disturbances

The intensity of the pain felt brought on changes in the manner in which they related to others, and with themselves. At the same time, the participants reacted in emotionally diverse manners to the pain, which, in many cases, had repercussions in the way they saw the world and their enjoyment of pleasant activities.

> *I'm always down. I get depressed. I feel very lonely, as if my life were about to end (…) I get terrible anxiety that makes me want to run away, or just leave and forget everything. I want to disappear from this world (…) This changes you completely (Marta, 45 years old).*

Some of the women mentioned that the decision to hide their emotions or act impulsively because of what they felt had lead to moments in which they had difficulties interacting with others:

> *This pain puts me in a bad mood. I don't feel like talking to anyone. I feel like I put distance between me and everyone (…) Since I got this disease, I have pushed people away in order to avoid their judgments of my pain. Honestly, I don't have a social life anymore. Sometimes I feel like I am alone with my disease (Sofia, 23 years old).*

The majority of the women stated that before being diagnosed, they thought of themselves as perfectionists, rational, controlling, autonomous, proactive, fast-paced and temperamental. Likewise, they asserted that the onset of the disease had influenced the perception they had of sociable and independent people:

> *I'm 45 years old, but in terms of pain, it's like I'm 60. For a while, I was going to programs for senior citizens and I felt like a little old lady (…) For me, it was really sad to see that I've been such a vital person, had three or four jobs, who would go out dancing all night and never get tired, in other words, I could do it all… but now my body has started to remind me of my limitations every day (Violeta, 45 years old).*

In this line, some of the research about the topic affirms that this type of situation may produce a vicious cycle in which the highest level of perceived pain increases the physical limitations, which, in turn, brings about feelings of disability, alters the perception of self-worth and raises stress levels (Armentor, 2017; Hoffman & Dukes, 2008; Lavielle et al., 2008; López & Mingote, 2008; Sener et al., 2016). These feelings of disability inhibit the resources that the women possess to face their disease and, as a consequence, they report increased levels of pain and emotional disturbances.

Onset of conflicts

In addition to the above mentioned, many women stated that the excess of support by their partners was bothersome and made them feel like people with a disability. Many of them felt that their relationship lacked balance because of the caregiving that was focused on them:

> *He sees that I'm going to get up from bed and tells me to wait, that he'll help me get up and fetch me whatever it is that I need… I tell him to let me do it myself, that I can do it. Once, I had a pain in my leg, and he wanted to bathe me, so I said no, I could do it myself (…) One day, I had a fight with him, and I told him to get out because he made me feel like a cripple, because I like to be independent and he was always trying to help me get up and do everything for me… and this puts me in a bad mood because I told him that I wasn't a cripple (Estela, 37 years old).*

As seen in Söderberg et al. (2003) research, an excess of family support, nevertheless, was perceived by some of the women as a reminder of their pain, fragility and dependence. Overprotection, in some of the cases, implied a loss of freedom as families felt they needed to be available to care for the women, and the women found that they needed the others' support in order to do certain activities. In this way, some of the participants mentioned that deciding to hide their emotions or acting impulsively according to how they were feeling meant that they sometimes had difficulties interacting with others.

Given that the women, in general, had more responsibilities at home, the changes in the distribution of roles and housework, in family activities and in their capacity to work (Söderber et al., 2003) negatively affected their family and social lives. At this point, many of them stated that they felt obliged to assume a more passive role and to reduce their daily activities in order to benefit their wellbeing and the stability of their family situations. In some cases, the women and their families were able to adapt, but in others, these relationships were damaged (Juuso et al., 2011; Rodham et al, 2010; Söderberg et al., 2003). The claim could be made that women with fibromyalgia go through changes in caregiving roles and a loss of freedom as well as the autonomy to carry out their activities. These results are consistent with the findings previously reported in the literature consulted (González et al., 2014; Jansen et al., 2012; Lange & Petermann, 2010; Nogueras et al., 2010).

Adapting to the disease

For many of the participants, the pain became a reminder of the fragility of their bodies and of the disease itself. Their bodies became a source of pain and not a means to experience pleasure:

> *I reject this disease. I say that I'm not sick, but all the same, I feel the pain… I mean, I don't want to give a name to these feelings (…) My view of this disease is clear: I don't accept it, but my body reminds me every day (Patricia, 43 years old).*

Others mentioned that they adapted more easily to the disease and to the changes when they began to fight against the pain instead of giving in to it. In this process of accepting, they recognized the pain as a part of their everyday lives that they couldn't estrange themselves from:

> *I was a complete victim. I was thinking: life is horrible, why me? Finally, I accepted that this was my burden that I had to deal with, and that was something that motivated me to keep going, to fight. As I went about accepting this disease, my quality of life got better (…) In the beginning it was difficult, but I think that it was a question of accepting, of knowing that, like there are people with big noses or small noses, big breasts or small breasts, well, this is just one of my characteristics. You know what I mean? (Natalia, 32 years old)*

The difficulties accepting these changes brought on by the disease makes many women assign a significance to fibromyalgia as a life condition that interferes with their social environment and their life projects (Rodham et al., 2010). As seen in previous studies, it was found that the grief that was experienced affects the manner in which the women live with the disease, and directly influences their expectations with respect to their health (González et al., 2014; Jansen et al., 2012; Lange & Petermann, 2010; Nogueras et al., 2010; Walker et al., 2006).

Accepting the disease allows many women to develop cognitive, behavioral and emotional repertoires that are geared toward problem solving. Denial, on the other hand, encourages the viewing of their pain as central element of their lives that is both threatening and uncontrollable (González et al., 2014; Lavielle et al., 2008; Rodham et al., 2010). The disease's symptoms, in addition to the low perception of their capacity to adjust to the changes, encourages alarmist thoughts and victimhood, as well as hypervigilant behaviors and avoidance (López &Mingote, 2008; Walker et al., 2006).

Searching for support networks

After learning their diagnoses, the participants of the study turned to informative support networks like self-help groups, the Internet and specialists. Establishing these networks allowed them to meet other people with similar experiences to their own with their disease and, at the same time, to modify their beliefs. Those that turned to people who had been diagnosed with fibromyalgia were able to clear up their apprehensions and feel accompanied in their process.

Family was perceived as a support network in that family members accompanied participants to their appointments; they helped remember the medication schedule; they exercised together; they gave massages, and were present during moments of pain. In this context, the social, familiar and work related support that was perceived conditioned the manner in which the study participants faced the disease. As has been reported in the literature, establishing informative, instrumental and emotional support networks allow the women with this health condition to clear up their doubts that they have about fibromyalgia, to feel accompanied in the process of their disease, and to express their emotions freely (Cardona et al., 2014).

In contrast, some women mentioned that the most difficult thing for them was perceiving a lack of support and misunderstanding of their pain by family members. When they did not receive the support they requested, some of the women confirmed that they felt alone in their pain, and they understood that the disease was something that only belonged to them. In accordance with previous research, it was demonstrated that a lack of understanding of the etiology of the disease, the stigma that these patients underwent in the health care system, and being pointed out by others, becomes a hindrance in communication processes (Armentor, 2017; González et al., 2014; López & Mingote, 2008).

As in Söderberg et al. study (2003), many of the participants in this study decided to present themselves as healthy in order to avoid judgment because of misunderstandings in their social environments. The lack of communication related to their needs provoked many of them to isolate themselves from their social circles, which limited their ability to find support networks and led them to signify the fibromyalgia as a health condition which they had to face on their own.

Coping styles in the face of the disease

Developing coping styles

With time, the women stated that they developed coping strategies like not letting the disease beat them, avoiding victimization and alarmist thoughts, controlling the consumption of medications, carryout Internet research, decentralizing the attention from the disease, trying out different treatments, self-regulating their emotions, continuing with their daily activities, relying on spiritual beliefs, learning to manage their pain thresholds, adjusting their eating habits and accepting the disease as a reality that they would have to live with.

> *I don't fight it anymore. I've turned it into my friend in order to work and get results (…) I try to do other things to avoid it; I don't concentrate on the pain, and you'll never catch me complaining; like I said, I've already taken it on as part of my life to be able to get along with it (Lina, 54 years old).*

Some of the participants understood that expressing their feelings was a strategy that let them prevent the onset of pain. Others, to the contrary, stated that the reason they decided to face their disease was related to the quest for their family members' wellbeing.

> *I decided to raise my awareness and tell myself that I have to be well for my children, that they need me (Violeta, 454 years old).*

Previous research has identified that active coping strategies, like not being defeated by the disease, decentralizing the attention from the experience of pain, communicating emotions, performing different leisure activities, establishing support networks and exercising, open the possibility of focusing on the pursuit their wellbeing and reporting lower levels of pain intensity and perception of disability (Biccheri et al., 2016; González et al., 2014; López & Mingote, 2008; Regier & Parmelee, 2015; Soriano et al., 2015; Ubago et al., 2008). These strategies probably facilitate a feeling of greater control over the symptoms, which, in turn, helps them see fibromyalgia as a health condition they can manage.

In contrast, those women that employ passive coping strategies, like falling back on spiritual beliefs, constantly avoiding the pain and abusing the use of medication, perceive the pain as undefeatable; they tend to isolate themselves socially, the give up performing pleasurable activities and develop pain avoidance behaviors (Biccheri et al., 2016; González et al., 2014; López & Mingote, 2008; Regier & Parmelee, 2015; Soriano et al., 2015; Ubago et al., 2008). Emotional discomfort that is derived from this situation affects the quality of their interpersonal relationships, raises the level of frustration concerning their health condition and diminishes the perception that they are able to carry out certain everyday activities.

Final considerations

The results of this research suggest that the implications of chronic pain in the quality of life in women with fibromyalgia can vary depending on personal factors, like age, level of education, their economic situation, beliefs about the disease and their coping styles; contextual factors, like the perceived social support, the availability of resources and cultural influences also influence variability. Factors like the intensity of perceived pain, the interference of pain in their daily life, emotional disturbances and negative cognition make the process of adjustment to the disease more difficult.

This panorama creates a need for each country, as part of their public policy, to establish care strategies that conform to the particular needs of these women. At the same time, it is important to develop intervention programs that allow health care providers to make use of a larger repertoire of tools to promote coping strategies for this population.

Future research could focus on methodologies with mixed approaches that would allow the contrast of variables like the length of time the diagnosis lasts, the intensity of the pain, the interference of pain in daily activities, the presence of emotional disturbances, the coping strategies and the quality of life of the women with this condition. Moreover, it is suggested that other studies should explore the impact that the disease has on the dynamics of couples' relationships.

One of the limitations of this research was that the homogeneity of the population studied limited the extrapolation of these findings to other conditions of the disease and social groups. Nevertheless, this research is presented as one of the first qualitative approaches to this phenomenon in Colombia, which may help other studies to continue exploring the implications that chronic pain has in the lives of women with fibromyalgia to greater depths.

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